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Running Head: Knowledge of AD in a community sample

A survey of community awareness of Alzheimer's disease: what are the common misconceptions?

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A survey of community awareness of Alzheimer's disease: what are the common misconceptions?

Community understanding of Alzheimer's disease (AD) is reported to have improved (Drachman, 2005), although such claims have proven difficult to substantiate empirically. Empirical data suggests that the size of the increase is probably less than claimed, selective for particular information, and variable across particular subgroups.

Newer approaches to assessing AD knowledge could be used to gain a better understanding of what the community knows about AD. Rather than conceptualising knowledge in terms of the *amount* known about AD (i.e., counting the number of correct responses), some studies have begun to unpack the nature of incorrect responses (e.g., Borrayo *et al*., 2007; Sullivan *et al*., 2007). These studies show what people think when they get things wrong, and by so doing, they provide information on misconceptions. This study involved an evaluation of the nature and extent of AD knowledge in a community sample, with the secondary aim of determining the influence (if any) of demographics on AD knowledge.

Volunteers were recruited at the Cairns show (n = 114). They either approached the stall or were approached by staff. Participants were mostly female (68%), middle-aged (M = 46; *SD* = 15 years), knew someone with dementia (80%) and were relatively well educated (51% had tertiary qualifications). Knowledge was assessed using a previously modified version of the Alzheimer's Disease Knowledge Test (ADK) (Sullivan and O'Conor, 2001). This test has 20 item multiple-choice items, each with five response choices, including an "I don't know" option.

On average, participants got eight ADK items correct (M = 8.2, SD = 3.5). There were group differences in ADK total scores due to age and education, but not gender or knowing someone with AD. More educated participants recorded

significantly higher ADK scores than less educated participants $t(112) = -2.59$, $p = .01$, and there was a trend towards older participants scoring higher than younger participants, $t(112) = -1.02$, $p = .06$.

As explained in Table 1 misconceptions, "knowledge gaps", and commonly held correct beliefs (CBs) were identified using cut-offs based on prior research (Smith *et al.*, 2004). Ten misconceptions, 7 CBs, and no knowledge gaps were identified. Table 1 shows that four misconceptions were held by a minority (< 40%), four were held by between 41% and 50%, and two were held by a majority (> 50%) of participants. Two CBs were held by over 85% of volunteers, indicating that a substantial majority of respondents got these items correct. One item was met both CB and misconception criteria.

Sullivan *et al*. (2007) identified fewer misconceptions (seven vs 10) and CBs (three vs seven) than was the case in this study, perhaps because of their relatively small sample size ($n = 36$). Common to both studies were three misconceptions and three CBs. The finding that there are some issues that are relatively well understood by members of the general community is positive. Such issues may need less attention in education campaigns, with the caveat that not *everybody* can be assumed to have this knowledge, merely that there is a higher likelihood that such information may already be understood.

The three misconceptions common to both studies concerned the diagnostic standard for a definitive AD diagnosis, the primary benefit of early diagnosis, and the best means of managing wandering. These potential areas of misconception, in particular, may require more focus when educating patients and the community. Such education could seek to provide the "facts" as well as exploring misattributions (Borrayo *et al*., 2007); for example, by talking through the merits of one ADK

response over another, since in some cases the misconceptions identified were not completely incorrect; instead they were answers that were not the *best* ones in the context of the others provided.

The most significant study limitation was use of a convenience sample. This sample was relatively well-educated sample and results may not generalise to less educated groups. The effect of this bias may be that community knowledge of AD is actually *lower* than that reported here; in which case these findings represent a *best* case scenario. In any case, it is clear that further community education about AD is needed, particularly among less educated people and on those issues identified as prone to misconception.

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Table 1

Endorsement rates for 10 misconceptions and 7 commonly held correct beliefs about Alzheimer's disease[*] in a community sample (n = 114)..

ADK response classification	% of sample
Misconceptions	
That prompt treatment may prevent worsening of symptoms [a,b]	57
That sharing feelings about wandering with the patient is a good way to manage wandering [b]	51
That treating depression will alleviate depressive symptoms and prevent further intellectual decline.[c]	42
The aluminium plays a role in the onset of AD	41
Confirmation of diagnosis can be achieved via mental status testing[b,d]	41
Underestimated the post-diagnosis life expectancy of people with AD	40
That patients react to their illness with a lack of awareness of symptoms	35
Overestimated the prevalence of AD	29
That personality changes were due to a combination of factors (an already unpleasant personality growing old, plus deliberate attempts by the patient to strike out due to frustration).	28
That research is the primary function of the Alzheimer's Association.	28
Commonly held correct beliefs	
When self-care becomes impaired, assistance to help the patient remain as independent as possible is advised [f, g]	86
Loss of memory is always found in AD [g]	86
Writing reminders may be useful for people with mild dementia	78
The cause of AD is unknown	69
The rate of AD is projected to increase proportionate to the number of people aged over 65. [g]	68
Persons with a relative with AD have an increased risk of being inflicted	60
Illness reactions can include depression, denial, and a lack of awareness of symptoms	51

Notes. [*] Misconceptions defined as endorsement of an "incorrect" response" by 25% or more of the sample; commonly held correct beliefs were define as endorsement of the correct response by 50% of more of the sample (n = 114).). Items on which ≥ 50% of people choose "I don't know" would have been identified as "knowledge gaps", but no items reached this criterion.

[a] as opposed to being important to rule out reversible causes of AD.

[b] also identified as a misconception by (Sullivan *et al*., 2007)

[d] as opposed to autopsy.

[e] as opposed to also potentially reacting with denial and depression (the correct answer here was "all of the above").

[c] as opposed to alleviating symptoms of depression only.

[f] as opposed to taking over tasks, or letting the patient do the task regardless of the outcome, or making plans for relocation to a nursing home.

[g] also identified as a commonly held correct belief by (Sullivan *et al*., 2007).